

RECOGNISING DISABILITIES AND BARRIERS!

Key findings from a Rare Barometer survey
on the impact of living with a rare disease

February 2025



10 July
8 Sept. 2024



9591
respondents
in Europe



1643
rare diseases
represented



43
countries

30 million people live with a rare disease in Europe. Every day, they face numerous barriers in accessing their social and independent living rights.

Recognising that they live with disabilities and addressing these barriers is crucial to enable their full participation in all areas of society.

This survey looked into the disabilities that people with rare diseases live with, and the challenges they face in obtaining disability recognition and independent living support.

It also explored the limitations they face in participating in society, including at school and work.

1 MOST PEOPLE WITH RARE DISEASES LIVE WITH DISABILITIES

Disability prevalence was estimated through three indicators: the Washington Group Short Set on Functioning (WG-SS), the Global Activity Limitation Index (GALI) and a self-identification question.



8/10

people with rare diseases
live with disabilities



WG-SS: 87% of the participants had 'some difficulties', 'a lot of difficulties' or 'could not at all' see, hear, walk, remember/concentrate, selfcare (dressing or washing over) or communicate; GALI: 83% of the participants were limited or severely limited in performing activities that people usually do because of a health problem during the last 6 or more months; Self-identification: 88% of the participants considered themselves as a person with a visible disability, an invisible disability or both. All participants (n=9591).

2 THEY LIVE WITH DIVERSE AND COMPLEX DISABILITIES

People with rare diseases have difficulties in a range of activities:



Seeing



Hearing



Walking or climbing steps



Remembering or Concentrating



Selfcare



Communication

Often time, they live with multiple disabilities, having difficulties in:

72% At least **2** activities

53% At least **3** activities

35% At least **4** activities



Left: the six domains of the Washington Group Short Set on Functioning (WGSS). Right: percentage of people with rare diseases who had 'some difficulties', 'a lot of difficulties' or 'could not do at all' in at least 2 domains, at least 3 domains or at least 4 domains of the WGSS - All participants (n=9591).

Most people with rare diseases live with invisible disabilities (**45%**) or with both visible and invisible disabilities (**25%**):



70% live with **invisible** disabilities

“I wish there was more attention towards rare diseases like mine, progressive, unfortunately invisible, but which causes many physical problems that are not considered in the evaluation of the percentage of disability.”

Person with a rare disease, Italy



Percentage of people who answered 'an invisible disability' or 'both visible and invisible disabilities' to 'Do you consider yourself as a person with...?' - All participants (n=9591).



80% experience **pain or fatigue**



Percentage of participants who responded 'some day', 'most days' or 'every day' to 'In the past three months, how often did you have pain?' or to 'In the past three months, how often have you felt very tired or exhausted?' - All participants (n=9591).



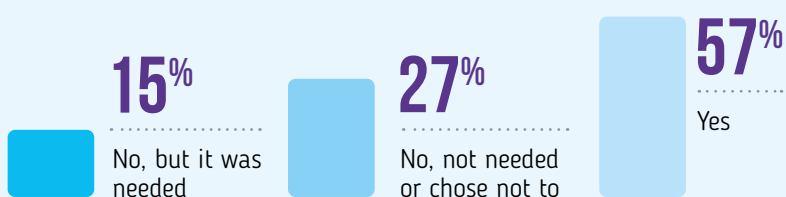
64% live with disabilities that are **progressive** or **dynamic**



Percentage of participants who declared that at least one of their functioning limitations, as measured by the Washington Group Short Set on Functioning (or WG-SS: seeing, hearing, walking, remembering/concentrating, selfcare or communication), was 'transient (occurring during acute episodes, periodic crises or relapses)' or 'worsening' - All respondents (n=9591).

3 THEIR DISABILITIES ARE NOT ADEQUATELY RECOGNISED

Disability assessments are not provided to all the people with rare diseases who need them:



'Have you ever undergone a disability assessment, which aims to assess and recognise disabilities?' – All participants (n=9,332); answer 'Don't know' was not included; answers 'No, but it was not needed' and 'No, I chose not to' were grouped.

Among those who were submitted to a disability assessment, 1 out of 3 did not get the results they expected, and in their opinion that was because:



61% Their disabilities were given a lower grade or percentage than expected



52% Their needs were underestimated



25% They did not obtain recognition for their disabilities

“ I was made to feel that, despite being completely disabled, I was able to cope with my everyday life on my own. It is humiliating that I am not believed, that I have to prove how bad I am, that I feel as if I am a welfare parasite.”

Person with a rare disease, Germany



Answer to the question 'In your opinion, was it because...' among participants who had a disability assessment and who said 'No' to 'Was the result of the assessment as expected?' (n=1607).

4 ...AND THEY DO NOT RECEIVE ADEQUATE SUPPORT

53% found it difficult or very difficult to obtain publicly funded support, and that was mostly because:



42% The application process was complex or lengthy



34% Their disabilities were not considered severe enough



29% They lacked information about the application process

“ I have been granted a disability certificate, but I still do not receive any kind of help. I have to work full time, even though it affects my health, and I have to force myself in my day-to-day life to be able to lead a normal life since nobody helps me.”

Person with a rare disease, Spain



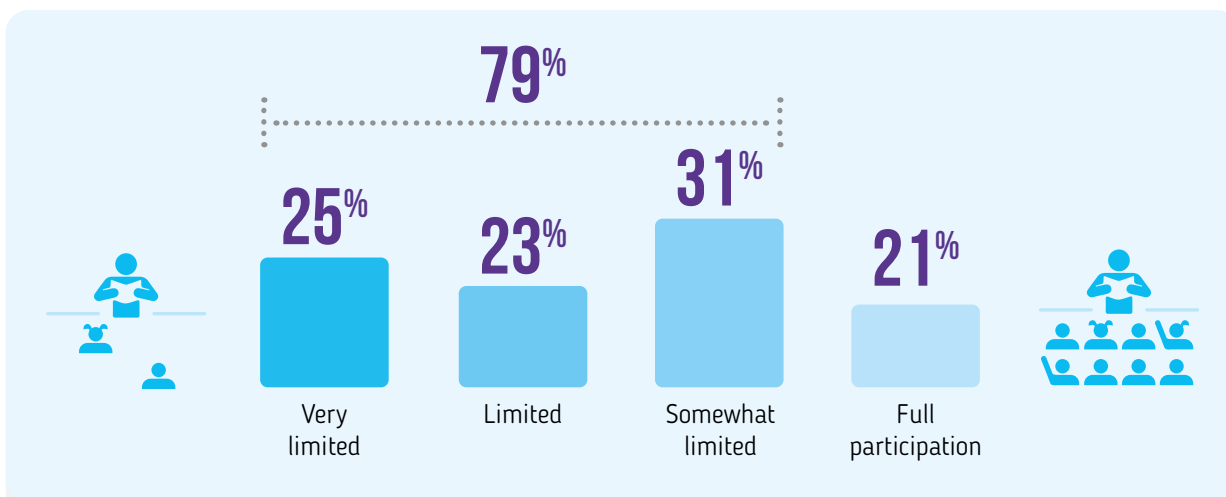
Answer to the question 'How difficult do you find it to obtain State support such as attendant care support, home support, financial support, assistive technology, mobility aids, etc.?' – All participants (n=9,591). 'What barriers are you facing in obtaining State support?' – All participants except those who answered 'Not applicable' to 'How difficult do you find it to obtain State support [...]?' (n=7,042).

5

PEOPLE WITH RARE DISEASES DO NOT TAKE PART IN SOCIETY ON AN EQUAL BASIS WITH OTHERS

Most students do not fully participate in education.

Based on the school module of the Child and Adolescent Scale of Participation (CASP), **79%** of the students participate in school in a somewhat limited, limited or very limited way.



Child and Adolescent Scale of Participation (CASP): 'Compared to other people the same age, what is your current level of participation in: educational activities; recreational activities; mobility; use of education materials & equipment; communication?'. CASP scores: Full participation=100-97.5; Somewhat limited=97.5-81.0; Limited=81.0-68.5; Very limited=< 68.5. Pupils and students (n=1548).

Unemployment of people with rare diseases is higher than in the general population.



23% of people with rare diseases are **unemployed**

Comparison: the unemployment rate in the general population of the European Union was **6.1%** in 2023¹.



Percentage of participants aged 16-64 who answered 'Unemployed' or 'Cannot work because of a disease' to 'What is your current situation?' (n=5332).

More information: eurordis.org/voices or rare.barometer@eurordis.org

Full report in English: tiny.cc/survey/RB_DailyLife

THANK YOU to all the people with rare diseases and family members who participated in the survey, and to Rare Barometer partners!

1. Unemployment rates by sex, age and citizenship, Eurostat (https://ec.europa.eu/eurostat/databrowser/view/lfsa_organ_custom_15225487/default/table?lang=en), consulted February 3rd 2025.